

BENEFITS AND RISKS OF GENETIC TESTING

For People Currently Living With ALS

Benefits	Risks
<p>Medical Benefits: Your genetic test results can help you find a clinical trial you may qualify for, which could lead to a better outcome for you or people who have ALS in the future.</p> <p>Family Planning Benefits: Understanding your genetic background can also help you make decisions about family planning. Depending on your age and stage in life, you can also work with a counselor or fertility specialist to develop a plan to reduce the chance that the variant gets passed down to your children.</p> <p>Psychological Benefits: If it turns out you do not have any mutations that are strongly associated with ALS, you might be relieved that your family members, even if they carry the same mutation, are less likely to develop ALS. You might also find relief in having a better idea of how your disease will progress, which will allow you to plan financially and psychologically.</p>	<p>Physical Risks: The physical risks associated with getting a genetic test are very small. All the test requires is a blood sample or, in some cases, a saliva sample.</p> <p>Legal Risks: When someone gets a genetic test, they might be opening themselves up to discrimination. In the U.S., the law protects against genetic discrimination in health insurance and employment, but not in disability, long term care, or life insurance. We recommend securing disability, long term care, and life insurance prior to getting a genetic test.</p> <p>Psychological Risks: Genetic testing results can create strain in marriages and among families. Your results can reveal information about your family members' chance of getting ALS. Also, your results may affect family planning, for example, if you carry a mutation that greatly increases the chance of your children getting ALS.</p>